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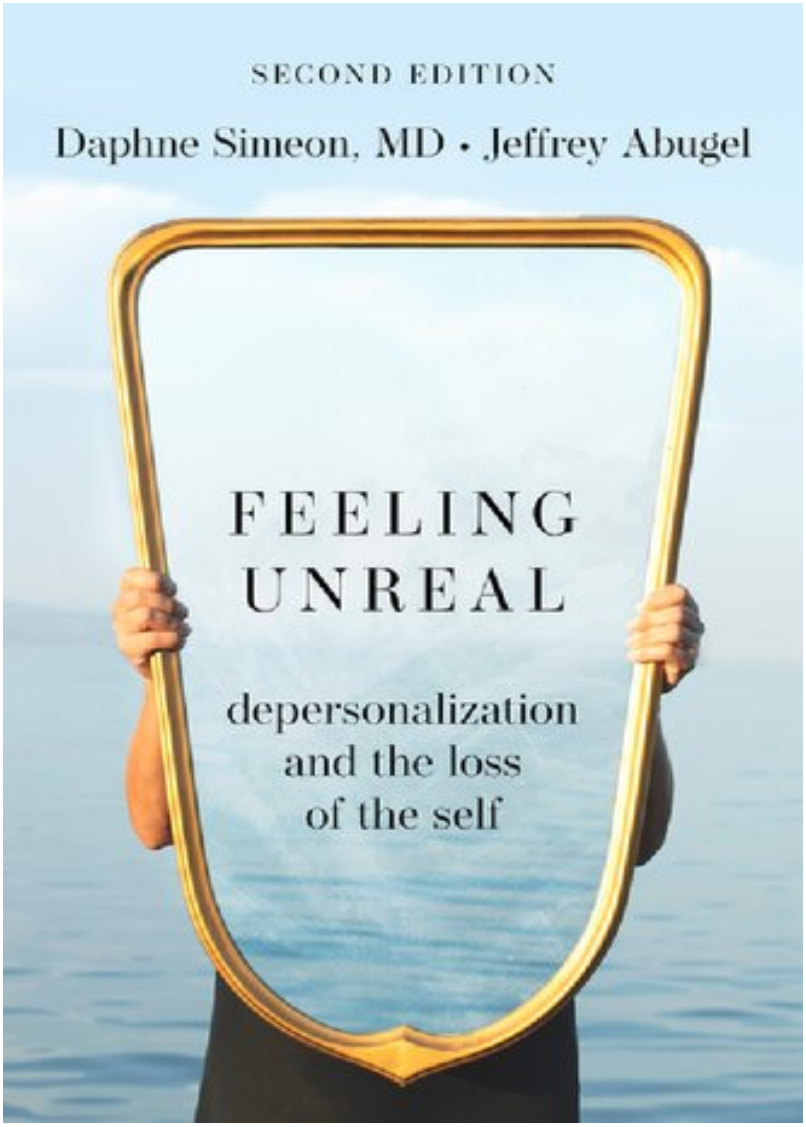

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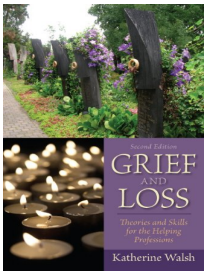

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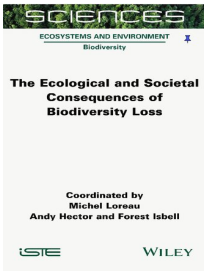

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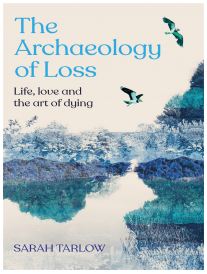

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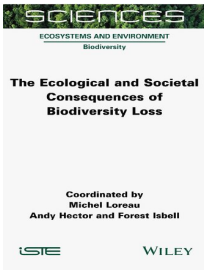

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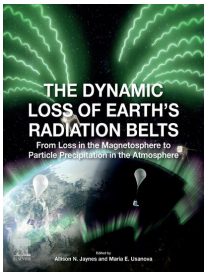

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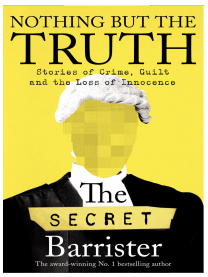

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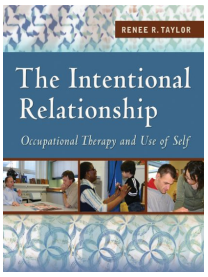

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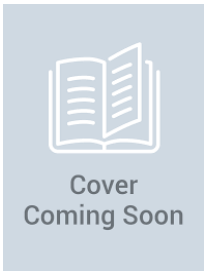

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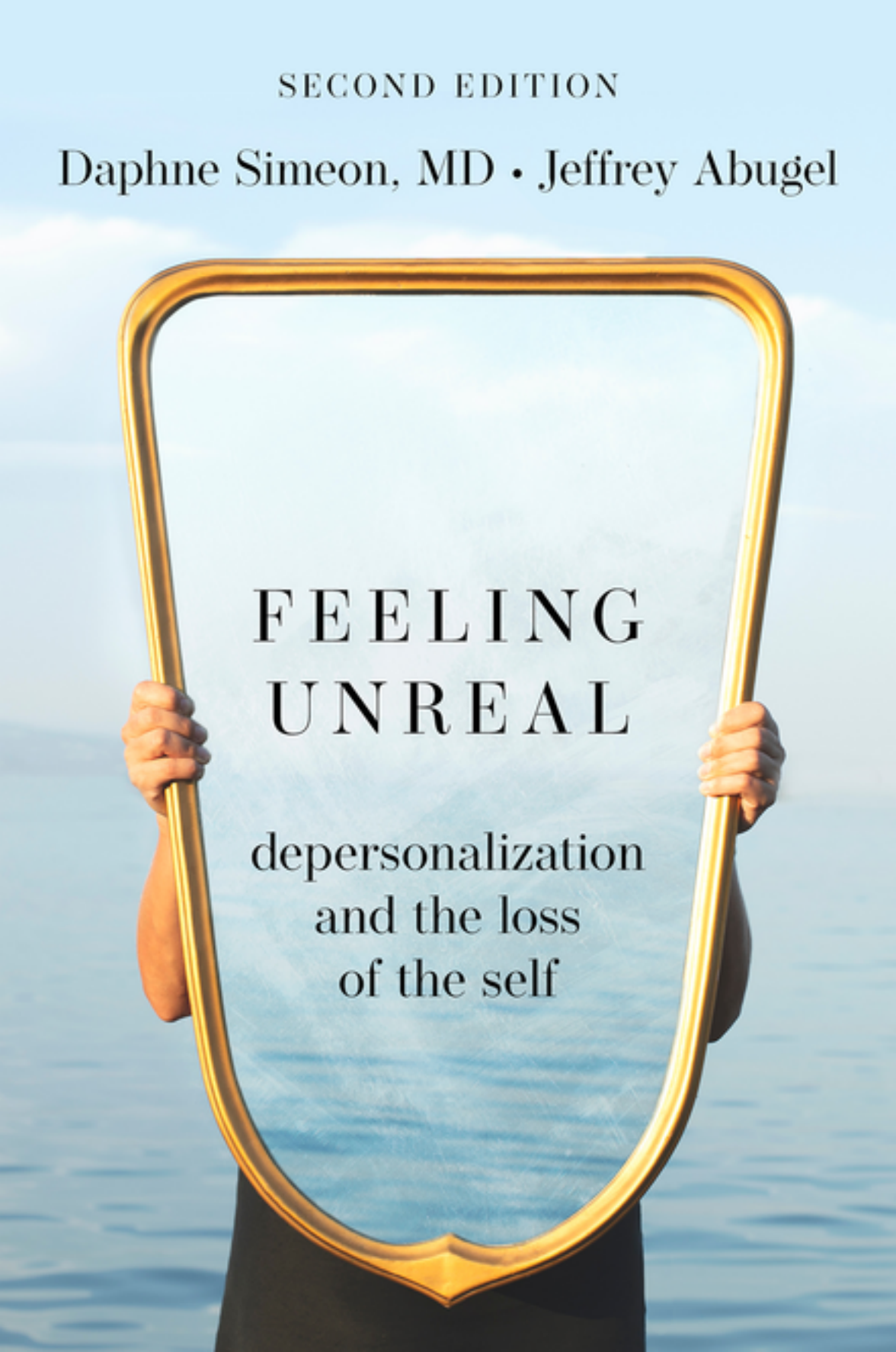

FEELING UNREAL

depersonalization and the loss of the self

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Depersonalization and the Loss of the Self

Second Edition

DAPHNE SIMEON, MD AND JEFFREY ABUGEL

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To my children.
—Daphne Simeon

To family and friends who have supported me through the years.
—Jeffrey Abugel

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Preface

When *Feeling Unreal: Depersonalization and the Loss of the Self* appeared in 2006, it was praised as a seminal work—the first book providing a comprehensive overview of the baffling condition then known as depersonalization disorder. The world has changed dramatically since. To some degree, what is now known as depersonalization/derealization disorder (DDD) is emerging from the shadows of obscurity, through continuing and expanding scientific inquiry as well as an explosion of social media. Major articles about DDD have appeared in print in the *Washington Post*, *Atlantic Monthly*, *Elle*, and *The Guardian*. The feature film *Numb*, starring Matthew Perry, brought the disorder into mainstream culture. In some quarters, the social isolation resulting from the COVID-19 lockdown brought depersonalization to the forefront of concern and discussion. And yet DDD's obscurity is slow to fade, and the condition remains relatively unknown or unacknowledged by many in the medical and other mental health communities.

Whether documented yesterday or a century ago, the core symptoms of DDD remain unchanged. Many people have felt "unreal" at some point in life, albeit fleetingly. For people with DDD, the world within, or the world around, is experienced as strange and unreal for prolonged periods of time. They feel detached from the sense of self they once took for granted and they struggle, sometimes for years, in search of answers, which can be difficult to come by. Imagine thinking without feeling, devoid of emotional connection to past or present. Imagine a heightened awareness of the thoughts parading through your head, or always watching yourself a step removed, interrupted periodically by a single emotion—the real fear of losing your mind. Living this way, vacuous, numb, and lost, wreaks havoc on individuals' inner lives. Outwardly they may appear rather normal, even well adjusted. But they know something is wrong, though they may not know what it is, so their lives often become façades of normalcy, masks to cover the unreality within.

The second edition of *Feeling Unreal* aims to present and discuss all that we now know about DDD, nearly two decades after the first edition. Our intention is to present a comprehensive and unbiased distillation of the broadening range of scientific material that has addressed depersonalization/

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derealization to date, as well as to examine the many philosophical, literary, religious, and spiritual reflections on depersonalized-like states of mind. *Feeling Unreal* is the culmination of decades of work seeking answers to questions that have remained elusive or unsynthesized for too long. As such, we hope that the book will be a valuable resource for sufferers and their loved ones, clinicians, students of depersonalization across disciplines, and all others intrigued by the state of mind that uniquely straddles psychopathology and being.

1

Strangers to Ourselves

We do not see things as they *are, we see them as* we *are.*

—Anaïs Nin

The idea that reality is subjective, constructed from our own perceptions, is an ancient concept. "We are what we think. All that we are arises with our thoughts. With our thoughts, we make the world," said the Buddha. In the same vein, Anaïs Nin's observation above originated in the Hebrew Talmud.

But what if our perceptions of our own thoughts, or the world around us, change in an inexplicable way? What if the world suddenly seems strange, and foreign? This is the story of a baffling but very real condition of the mind that plagues millions of people worldwide. It isn't depression, or anxiety, though it can sometimes appear as a symptom of these better-known conditions. Often, it emerges with cruel ferocity as a chronic disorder completely unto itself. Its destructive impact on an individual's sense of self is implied in its very name—depersonalization.

Depersonalization/derealization disorder (DDD) is a serious disruption in a person's experience of the self that alters their entire world. Take the case of Ron, a 39-year-old magazine editor living in a coastal city. To his peers, Ron's life is practically heaven on earth. He's bright, funny, and successful at his job. With an apartment near the beach and plenty of friends, he is living a life that is envied by many. But Ron has a problem. And each day when he returns to his upscale neighborhood in time to see the sun setting, he wonders how long he can maintain what he has. He wonders if tonight will be the night he finally slips into the isolated hell of insanity.

Ron's problem is a mental one, and he knows it. Trapped within the confines of his mind, he is too aware of every thought passing through it, as if he were outside, looking in. At night he often lies awake ruminating endlessly about what's wrong with him, about death, and about the meaning of existence itself. At times his arms and legs feel like they don't belong with his

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body. But most of the time, his mind feels like it is operating apart from the body that contains it.

While he can interact with others who have no idea that anything is wrong, Ron lives without spontaneity, going through the motions, doing what he thinks people expect him to, glad that he is able to at least *appear* normal throughout the day and maintain a job. He studied drama briefly while in college and remained enamored of Shakespeare and literature, but an emerging self-consciousness eventually robbed him of his ability to act. Now he feels as if *all* of his life is an act—just an attempt to maintain the status quo.

Recalling literature he once loved, he sometimes pictures himself as Camus's Meursault, in *The Stranger*, an emotionless character who plods through life in a meaningless universe with apathy and indifference. He's tired of living this way but terrified of death. So he's settled into a predictable routine whereby work serves as a necessary diversion, and happiness is a dearly departed illusion. Dead people can't be happy, he thinks. To be happy, one has to feel, and Ron has not felt anything but fear, confusion, and despair for a long time.

In his autobiographical account of his battle with debilitating depression, *Darkness Visible*, William Styron writes: "Depression is a disorder of mood, so mysteriously painful and elusive in the way it becomes known to the self—to the mediating intellect—as to verge close to being beyond description."[1] The writer's skills are tested when writing about what Styron calls "a shipwreck of the mind." The wreckage caused by depersonalization is equally indescribable to anyone who has not experienced it. Phrases like "things feel unreal to me," "I feel detached from myself," and "my voice sounds different to me" are enigmatic to normal people yet often quite understandable to depersonalized individuals.

Most of us can imagine our darkest fear, such as being buried alive, or locked in a room full of rats or spiders. Most of us can remember moments of intolerable grief or unbridled terror, whether they occurred in waking life or in nightmares. We can remember being unable to "shake" some awful sensation in the conscious hours after a particularly bad dream, or feeling "unreal" in the face of a sudden tragedy or loss. For the most part, depersonalized people are actually living every day with the fear and unreality of a dream state come true. Inner and outer worlds seem strange and foreign, resulting in an altered sense of selfhood that dominates their mental lives.

Our sense of familiarity with ourselves, our sense of past, present, or future, who we are, and how we fit into the world around us enables us to live

from day to day in relative stability, with purpose, sanity, and reason. But people with chronic depersonalization are never quite sure who they are, in a sense. As such, they can find themselves in a life of going through the motions robotically, often attempting to appear "normal," wondering if others can see through their façade to the inexplicable disconnection that pervades their existence.

Tom, a 44-year-old sales executive, feels that he gets through his job using about 10% of his brain capacity:

> I'll sit in an important meeting and be asked crucial questions, and somehow I come up with the answers. But I'm not really there. It's as if nothing is real, myself or the meeting I am in. I look out the window 40 stories up and wonder where the sky ends. Or I see myself sitting in this meeting, discussing bottom lines and sales promotions as if they actually had meaning to me. It's more than daydreaming. It's like I'm too aware of certain larger aspects of reality. In the face of the infinite sky above me, or infinite time before and after my short existence, how could such things as my job have any meaning at all? Doesn't anyone else ever wonder about this stuff?

Tom's sense of detachment from everything that is immediate and vivid in the day-to-day world, and his over-preoccupation with the nature of existence, is something often experienced by depersonalized people. Says Cheryl, a 33-year-old fabric designer:

> I sometimes feel like I'm from Mars. . . . Being human seems strange, bodily functions seem bizarre . . . My thoughts seem separate from my body. At times, the most common, familiar objects can seem foreign, as if I am looking at them for the first time. An American flag, for instance. It's instantly recognizable, and immediately means something to everyone. But if I look at it for more than a moment, I just see colors and shapes on a piece of cloth. It's as if I've forgotten ever seeing the flag before, even though I'm still aware of what my "normal" reaction should be.

This sense of strangeness about familiar objects outside of one's self is known specifically as *derealization*, the flip side of the depersonalization experience. "What's so troubling to me is that if I were seeing these things for the first time, like a child, there should be some sense of wonderment, but

there isn't," Cheryl adds. "I know that there's something wrong with me, and all it does is fill me with fear, especially the fear of being taken away screaming in a straitjacket."

Louise is a 29-year-old grade school teacher whose experiences of depersonalization permeate all the ways in which she relates to her body and her movements, as well as her whole visual experience of the world. Her depersonalization started when she was around 10, at which time she felt that whenever she lifted up her legs or arms, her body felt weightless, and she began to float. She says: "For me, it can be a very visual experience. It's like I'm wearing glasses that I can't see through, like there is a zipper to unzip." She no longer feels much; she describes herself as numb, and it's rare for her to cry even when she feels like it. Her body does not feel like a part of her: "I sometimes smack my hand or pinch my leg just to feel something, and to know it's there." Louise often feels like one part of her is "acting." At the same time, "there is another part 'inside' that is not connecting with the *me* that is talking to you," she says. When the depersonalization is at its most intense, she feels like she just does not exist. These experiences leave her confused about who she really is, and quite often she feels like an "actress" or simply "a fake."

Phil, 42, owns a successful business and is the father of two. He first experienced depersonalization when he was 17, and in the beginning the episodes would come and go. For the past 15 years or so, however, his depersonalization has been constant, at times more intense than at others. Like Louise, he eloquently describes the many facets of his self-experience that have become chronically distorted by depersonalization. He has thought about his condition a great deal and has researched it on his own, as fervently as any doctor he has met to date. When he tries to explain his experiences to a professional, or to someone close to him, he does so in terms of the distinct domains of his selfhood that are affected:

Emotions: "I want to feel things like everyone else again, but I'm deadened and numb. I can laugh or cry but it's intellectual; my muscles move but I feel nothing."

Body: "I feel like I'm not here, I'm floating around. A separate part of me is aware of all my movements; it's like I've left my body. Even when I'm talking I don't feel like it is my words."

Mind: "My mind and my body are somehow not connected; it's like my body is doing one thing and my mind is saying another. Like my mind is somewhere off to the back, not inside my body."

Vision: "It's like glass over my eyes, a visual fog totally flat and two-dimensional."

Agency: "I feel I'm not really here, I'm not in control of my actions. I'm just going through the motions, like a robot."

People like Phil may suffer from chronic DDD for many years, visiting a variety of doctors, psychiatrists, and therapists. Typically, health professionals are not only unable to offer much relief, but they rarely even offer a reassuring label for the condition. Patients are commonly told that they suffer from some kind of anxiety or depression and that what they feel is secondary to their main problem.

The frightening absence of feeling often encountered in DDD also can create a somewhat paradoxical state of mind. On one hand, selfhood, and with it the individual's relation to the outer world, seems to deteriorate, leaving the sensation of "no-self." Conversely, a heightened awareness of inner experiences, like the thoughts running through one's head, or visceral sensations that cannot be ignored, can result in a hyper-monitoring of the self, a self that no longer feels familiar, grounded, or unquestioned. Strongly held desires and beliefs, vivid memories, strong emotions that were naturally sparked by the senses now all seem like illusions, far away, without real meaning, somehow false. Familiar mental images are reduced to movie-screen images devoid of the smells, sounds, and punch that once made them click. Ideas and memories that once had emotional meaning are now experienced with alien-like awareness and little feeling, while the sufferer remains intellectually aware that this altered perspective is anything but normal. This lack of "embeddedness" that accompanies a normal sense of self can leave one feeling lost, vulnerable, and fearful.

"When I try to explain this, it sounds like a complete contradiction," says Joanne, a 35-year-old mother of three. "Minutes can seem like hours to me when every thought, no matter how insignificant, is weighed and overly present. It's like my thoughts are on a big movie screen in huge type, or shouted at me in a loud unpleasant voice. Yet at the same time, my lifetime, and all the lifetimes before and after mine, seem to last just seconds in the scheme of things. I try to recapture the feeling I had when I was young, that life was rich with promise. I looked forward to building memories to cherish in my old age. But now it all seems so short and empty, as if all the experiences I did enjoy to this point have been erased and I'm just existing in this very second . . . there is no past, no future. Instead of being rooted in this

world, enjoying my children and my life, all I can think of is how transient it all is."

"I'd really rather have cancer than this," Joanne concludes. And she's not alone in this sentiment: others who are chronically depersonalized have made the exact same statement. "With a disease that people know, you get some degree of empathy. But if you try to explain this, people either think you're crazy or completely self-absorbed and neurotic. So you keep your mouth shut and suffer silently." Indeed, depersonalized individuals often say they would give anything to live their lives again with less scrutiny of existence and more spontaneity. While Socrates may have concluded that "the unexamined life is not worth living," the *overly* examined life, as experienced by the people we've met so far, is often too painful to endure.

Hardly a New Disorder

Depersonalization, as a human experience, is nothing new. It has traditionally been viewed as the mind's natural way of coping with overwhelming shock or stress, or intolerably inhumane living conditions. In such instances, the mind detaches itself from the surroundings for the purpose of sheer survival. But strangely, depersonalization can also appear spontaneously, without any apparent trigger. Possible causes of onset have only been researched in depth in the past couple of decades, though theories have proliferated for over a century (we'll cover these causes in more detail later). Some people can recall exactly how and when the problem began and whether or not it was tied to a specific event. For others, the condition may have begun so early in life that it is simply all they have ever known. In such cases, depersonalization becomes a safe void where nothing affects them, but at high price: when they'd like to feel, they can't. They become what some have come to call "the living dead."

The word *depersonalization* itself, in a diagnostic sense, refers to both symptoms and to the full-blown psychiatric disorder of DDD. Ludovic Dugas, a psychologist and philosopher who often wrote on the topics of memory and déjà vu, is most often credited with first using the term in its present context, in the late 1890s.[2] However, Dugas had first seen the word in a popular literary work of the era, *The Journal Intime*, by Henri Frédéric Amiel (1821–1881). This journal, the voluminous diary of an introspective and obscure professor, was published posthumously. One particular entry

helped to define the nature of depersonalization for all time: "And now I find myself regarding existence as though beyond the tomb, from another world. All is strange to me; I am, as it were, outside my own body and individuality; I am depersonalized, detached, cut adrift. Is this madness?"[3]

Other more renowned individuals later recognized depersonalization/derealization (dpdr) as very concrete human experiences. Sigmund Freud experienced a vivid encounter with derealization while visiting the Acropolis during a trip to Athens in 1904.[4] We'll take a closer look at Freud's experience, as well as dpdr's presence in psychology, history, and philosophy, in subsequent chapters.

In years that followed, renowned psychologists either touched on the subject of dpdr in books or issued lengthy papers on it in nearly every major language. In the 1930s, a medical textbook entitled *Modern Clinical Psychiatry* first included depersonalization within the context of schizophrenia. Revised years later in the 1960s, it provided a particularly insightful description:

> Depersonalization, a pervasive and distressing feeling of estrangement, known sometimes as the depersonalization syndrome, may be defined as an affective disorder in which feelings of unreality and a loss of conviction of one's own identity and of a sense of identification with and control over one's own body are the principal symptoms. The unreality symptoms are of two kinds: a feeling of changed personality and a feeling that the outside world is unreal. The patient feels that he is no longer himself, but he does not feel that he has become someone else. The condition is, therefore, not one of so-called transformation of personality. Experience loses emotional meaning and may be colored by a frightening sense of strangeness and unreality. The onset may be acute, following a severe emotional shock, or it may be a gradual onset following prolonged physical or emotional stress. It is more frequent in personalities of an intelligent, sensitive, affectionate, introverted, and imaginative type. The patient may say his feelings are "frozen," that his thoughts are strange; his thoughts and acts seem to be carried on mechanically as if he were a machine or automaton. People and objects appear unreal, far away, and lacking in normal color and vividness. The patient may say he feels as if he were going about in a trance or dream. He appears perplexed and bewildered because of the strangeness of unreality feelings. He has difficulty in concentrating and may complain that his brain is "dead" or has "stopped working."[5]

To be accurate in terms of what's known today, the description should have ended there. But, in line with older theories about depersonalization, the textbook postulated that depersonalization was not a specific condition outside of other neurotic and psychotic states and that it occurred more commonly in women and in puberty, and recommended electroshock therapy as the effective form of treatment. Times and attitudes have changed. It is now thought that the condition occurs about equally across genders, at many stages of life. Chronic dpdr is now recognized as a unique disorder of its own standing, depersonalization/derealization disorder (DDD), rather than a condition secondary to other ailments.

Unlike the early days of studying the mind, today's field of psychiatry has developed a reference book, the *Diagnostic and Statistical Manual of Psychiatric Disorders* (*DSM*), revised periodically to stay current. These revisions list the latest criteria for making an accurate diagnosis of virtually any known mental illness based on more recently gathered evidence. Early versions of the *DSM* from the 1950s and 1960s mentioned depersonalization as a dissociative reaction or syndrome, classified in the category of neurotic disorders. From 1980 on, chronic depersonalization was placed within the new category of dissociative disorders, yet the *DSM* offered few specifics about the condition. But today that's changed. According to the latest edition, *DSM-5-TR*,[6] DDD is described as follows.

An individual suffering from depersonalization may experience:

- Detachment from one's whole self or from aspects of the self.
- Detachment from feelings.
- Detachment from thoughts.
- Detachment from the whole body or body parts.
- Detachment from sensations.
- Diminished sense of agency.
- A split self, one part observing and one participating.

Sufferers of derealization may experience:

- Detachment from the world (people, objects, or all surroundings).
- Feeling as if one is in a fog, dream, or bubble.
- The sensation of a veil or glass between the self and the world around.
- Surroundings that seem artificial, colorless, or lifeless.

- Visual distortions (blurriness, changes in visual field, dimensionality, or size of objects).
- Auditory distortions (voices or sounds are muted or heightened).

Patients may experience symptoms of one or both elements for a diagnosis of DDD to be made. And symptoms may be episodic or recurring (see Chapters 3 and 4 for more about symptoms and diagnosis). *Unreality* and *detachment* are the essence of dpdr, despite the multitude of symptoms that have been recorded over time. People may have difficulty describing their symptoms and may fear that their experiences in fact signify that they are losing their mind, going "crazy."

At some point in their lives, many adults will experience a brief episode of dpdr, usually precipitated by severe stress or trauma. Depersonalization has been found to occur transiently in one-third to one-half of student populations.[7] Transient depersonalization, lasting seconds, minutes, or even hours, can readily occur in otherwise "healthy" individuals under extreme conditions of sleep deprivation, sensory deprivation, travel to unknown places, or acute intoxication with marijuana or hallucinogens. It also occurs in about one-third of people who have been exposed to life-threatening danger, and about 10% of patients hospitalized for various mental disorders.[8] Depersonalization has been found to occur, at least fleetingly, in 50% to 70% of the general population.[9] Most often, initial depersonalization goes away as mysteriously as it came, but sometimes it becomes more chronic, with an enigmatic life of its own. Research shows that approximately 2% of the general population suffers from chronic depersonalization that rises to the level of a psychiatric disorder.[9]

Sudden depersonalization is likely to make a person think they're going insane. When it occurs after they've taken an illicit drug, they often think they've suffered brain damage. No longer grounded by familiar sensations or surroundings, they feel as if they're losing their grip on reality. But unlike people with psychotic conditions like schizophrenia, they are not going insane at all. They are, if anything, suddenly *overly aware* of reality and existence and of the ways in which their own experience is a distortion of the "normal" sense of a real self.

Depersonalization, in fact, resembles a sort of altered "consciousness," akin to the "awakening" that in some cultures is thought to be a level of spiritual growth. This is touched upon in the *DSM-5-TR*, which

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